

Disability and Rehabilitation Services in India: Issues and Challenges

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ABSTRACT

Disability is an important public health problem especially in developing countries like India. The problem will increase in future because of increase in trend of non-communicable diseases and change in age structure with an increase in life expectancy. The issues are different in developed and developing countries, and rehabilitation measures should be targeted according to the needs of the disabled with community participation. In India, a majority of the disabled resides in rural areas where accessibility, availability, and utilization of rehabilitation services and its cost-effectiveness are the major issues to be considered. Research on disability burden, appropriate intervention strategies and their implementation to the present context in India is a big challenge. Recent data was collected from Medline and various other sources and analyzed. The paper discusses various issues and challenges related to disability and rehabilitation services in India and emphasize to strengthen health care and service delivery to disabled in the community.

Keywords: Challenges, disability, India, issues, rehabilitation services

Introduction

Any restriction or lack of ability to perform an activity in a manner or within the range considered normal for the human beings, resulting from impairment is termed as disability. Impairment concerns the physical aspects of health; disability is the loss of functional capacity resulting from an impairment organ; handicap is a measure of the social and cultural consequences of an impairment or disability.^[1] The types of disability include loco-motor, hearing, speech, visual and mental disability. Recent development is the International Classification of Functioning, Disability and Health^[2] developed by WHO in 2000 which has been used in the Multi-Country Survey Study during 2000 and 2001 and the World Health Survey Program in 2002 and 2003 to measure health status of the general population in 71 countries.^[3] The domains here are classified into body, individual, and societal perspectives by the conceptual components that includes body functions and structure, activity and participation along with contextual factors that includes a list of environmental and personal factors. The ICF considers that every human being

can experience some degree of disability and it is a continuous process from attainable level of health. With this background, the paper discusses various issues and challenges related to disability and rehabilitation services in India.

Review of Literature

Recent data was collected from Medline and various other sources. Information gathered was summarized for Indian context and analyzed for discrepancies. Information was depicted under categories of problem burden of disability and its socio-demographic characteristics, determinants, service delivery under community-based rehabilitation, challenges ahead and recommendations to address the problem in the country.

Problem Burden

Globally, around 785-795 million persons aged 15 years and older are living with disability based on 2010 population estimates. Of these, the World Health Survey estimates that 110 million people (2.2%) have very significant difficulties in functioning while the Global Burden of Disease Survey estimates 190 million have (3.8%) have severe disability. Including children, over a billion

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people (about 15% of the world's population) were estimated to be living with disability.^[4]

Systematic research into prevalence and determinants of disability has been scanty from India although it is an important public health problem. Disability is the best example of the iceberg phenomenon of disease. This is because of difficulty in identifying the mild and moderate degrees of physical and mental disability which are unrecognized by the health care delivery system and the survey team members.^[5] The WHO estimates that 10% of the world's population has some form of disability.^[6] In contrast, the National Sample Survey Organization (NSSO) report^[7] and Census data of 2001^[8] stated that its prevalence was as low as 2% in India. A recent community-based study in India found the prevalence of all types of disability as 6.3% out of which mental disability was found to be the most common type of disability (36.7%).^[9]

The disability prevalence varies in different age groups and urban-rural areas. The burden of disability is more among the geriatric (>60 years) age group with 6401 and 5511 per lakh population in rural and urban areas respectively.^[7] A study in Chandigarh reported that 87.5% of elderly people had minimal to severe disabilities.^[10] Another study in Dehradun showed that visual disability was the most common (74.1%) among the geriatric age group.^[11] A community-based study conducted in Rajasthan among children below 14 years found that 7% of them had at least one or other form of disability.^[12] Another study in Gorakhpur found that in children below the age of 6 years the disability rate was 7638 per lakh population.^[13] In India, NSSO reported that a total of 1,40,85,000, and 44,06,000 people are disabled in rural and urban areas, respectively. Overall, 1846 and 1499 per lakh population had any type of disability during the survey in rural and urban areas respectively.^[7] With respect to gender distribution, some studies showed proportionately more disability among males,^[7] while some other studies more among females.^[9] Lack of education among disabled is an important barrier for effective delivery of services and 54.7% of disabled belonged to illiterate category according to NSSO 2002 survey findings.^[7] The differences observed in various studies are mainly due to difference in methodology adopted, conceptual framework, the scope and coverage of surveys undertaken, operational definitions used for various types of disabilities along with difference socio-cultural, and risk factors prevailing in that area. Social attitudes and stigma, international evidence, gap driven by mental retardation, and mental health measurement are also important factors related to prevalence of disability.

Determinants

The global burden of disease study (GBD) provides a standardized approach for epidemiological assessment and uses a standard unit called as the disability adjusted life year (DALY), to aid international comparison. DALYs express years of life lost to premature death and years lived with disability (YLD), adjusted for the severity of disability. One DALY is one lost year

of healthy life.^[14] Only about one-quarter of the total disability burden at global level is due to Group I conditions that includes communicable, maternal and perinatal factors reported mainly from South Saharan Africa and India. In terms of numbers or years lived with a disability, there is more non-communicable disability in India than in the Established Market Economies. As countries pass through the health transition, the distribution of YLD shifts away from Group I conditions.^[15] In 1998, an estimated 43% of all DALYs globally were attributable to non-communicable diseases and in low and middle income countries, the figure was 39%.^[16]

In India, although both communicable and non-communicable diseases are prevalent in urban and rural areas, there is paucity of data on these factors causing various types of disability and to assess its rural-urban differences. But, the deaths from non-communicable causes are projected to almost double from about 4.5 million in 1998 to about 8 million a year in 2020. There is a steep increase in the burden of non-communicable diseases, the phenomenon of epidemiological transition, which is largely driven by population ageing, augmented by the rapidly increasing numbers of people exposed to tobacco, and other risk factors such as obesity, physical inactivity, and heavy alcohol consumption.^[16]

Almost one quarter of the global total years Lived with Disability are because of diseases and injuries occurring among young children, but significantly more (36%) arise from conditions incurred at ages 15-44. As this is the productive age group, they need more attention as far as support to family members and their quality of life is concerned. Another 15% is due to incidence of disease or injury at older adult ages (45-59), and a comparable amount among the elderly. The high prevalence of chronic conditions in the elderly along with the shift occurring in the age structure accounts for increasing concern about disability among this vulnerable population in India. The largest number of YLD reported at ages 15-44, partly reflecting the population size, occurred in China and India. Owing to the combination of population size and high disease and injury rates, India and China accounts for nearly 40% of the total years lived with a disability.^[17] At this juncture, it is important to estimate the magnitude of the problem, various causes for different types of disability, status of rehabilitation services, and structure and functioning of health care delivery system pertinent to disability in India.

Community-Based Rehabilitation

Alma Ata declaration on 1978 stated that comprehensive primary health care should include promotive, preventive, curative, and rehabilitative care. There are three approaches to rehabilitation, namely institution based, outreach based, and community based. The major objective of Community Based Rehabilitation (CBR) is to ensure that people with disabilities are able to maximize their physical and mental abilities, have access to regular services and opportunities, and achieve full integration within their communities.^[18] CBR is a comprehensive approach

at primary health care level used for situations where resources for rehabilitation are available in the community. In addition to transfer of knowledge related to skill development in various types of rehabilitation methods, community also will be involved in planning, decision making, and evaluation of the program with multi-sectoral coordination. Besides, referral system will be there for those disabled who cannot be managed at community level and referred to district, provincial, and national levels.

Disability limitation at early stage when they are amenable to preventive and rehabilitative measures, so that progression to severe disability can be minimized is a vital component in rehabilitation of disabled. It has shown that very few disabled people gets benefit from rehabilitation services in India.^[7,19] In general, of people with disability, 1/3 needs no rehabilitation, 1/3 can be helped through CBR alone and 1/3 needs specialized referral services. Basic principles of a CBR program for the disabled include inclusion, participation, sustainability, empowerment, and advocacy. These principles are overlapping, complementary, and interdependent and they cannot be addressed in isolation.

There are many measures initiated by Ministry of Social Justice and Empowerment and Health and Family Welfare in India.^[20]

1. District Rehabilitation Center (DRC) Project started in 1985.
2. Four Regional Rehabilitation Training Centers (RRTC) have been functioning under the DRCs scheme at Mumbai, Chennai, Cuttack, and Lucknow since 1985 for the training of village level functionaries and DRCs professionals, orientation and training of State Government officials, research in service delivery, and low cost aids. Apart from developing training material and manuals for actual field use, RRTCs also produce material for creating community awareness through the medium of folders, posters, audio-visuals, films, and traditional forms.
3. National Information Center on Disability and Rehabilitation
4. National council for Handicapped Welfare
5. National Level Institutes—NIMH, NIIH, NIVH, NIOH, IPH.
6. A new scheme District Disability Rehabilitation Centre for persons with disabilities launched by the Hon'ble Minister of Social Justice and Empowerment, Government of India in Jan/Feb. 2000 is a step towards providing rehabilitation services and implementation of Persons with Disability Act. 1995. The Government has decided to set up District Disability Rehabilitation Centres (DDRCs) in a phased manner. Presently, 199 DDRCs have been sanctioned and 100 new DDRCs are to be set up during the remaining two years of the 11th Plan. The DDRCs were established with the objective of providing comprehensive services to the persons with disabilities at the grass root level. The services include awareness generation, survey, identification and early intervention, counseling, assessment of need for assistive devices, provision/fitment of assistive devices, and their follow up/repair, therapeutic services like Physiotherapy, Occupational Therapy and Speech Therapy, referral and

arrangement for surgical correction through Government and Charitable Institutions, facilitation of issue of Disability Certificates and bus passes, sanction of bank loans, and promotion of barrier-free environment.^[21]

7. The National Policy for Persons with Disability 2005 is the recent development and welcome step by the Government of India.

Service Delivery System for Community-Based Rehabilitation

This will require coordinated efforts by ministries, local, district and provincial authorities, and nongovernmental organizations in the different sectors involved in rehabilitation. For the majority of the disabled (70%), interventions can be done effectively at the community level by local supervisors/school teachers. A recent study among mentally disabled adolescents showed that psychosocial intervention increases the quality of life and reduces the disability severity.^[22] Additional services should be set up in response to the needs of the community. At district or provincial level which caters around 20% of the disabled requires general physicians, intermediate level supervisors, orthopedic technicians, resource teachers and vocational trainers. National level professionals will be involved in delivery of complex rehabilitation services as well as training and supervision of personnel for district, provincial, and national levels.

Disabled individuals in the community face many social problems. Improving the quality of life of people with different grades of various types of disabilities is a difficult and challenging task. Disabled individuals will be neglected in the community because of inaccessibility to services and lack of opportunities like health services, schools, vocational education programs, and jobs. In Chamarajnagar, Karnataka, a local Non Governmental Organization (NGO) assisted people with disability and their families to construct accessible toilets.^[4] Besides, social segregation of disabled is common in the community. This is because of deep rooted fears and beliefs acquired from cultural and religious factors. Overall, in reality it is a social problem where the disabled becomes a liability to the society. For improving the quality of life of persons with disabilities, research will be supported on their socio-economic and cultural context, cause of disabilities, early childhood education methodologies, development of user-friendly aids and appliances, and all matters connected with disabilities which will significantly alter the quality of their life and civil society's ability to respond to their felt needs.

Challenges

The major challenge includes understanding the concept of disability and acceptance of CBR as a valid intervention. Hospital-based rehabilitation services will lead to mystification of knowledge with social isolation and low efficiency of services which will benefit fewer disabled. Prioritization of resources like finance, manpower, and materials will be another important issue to be considered. Poor planning and management of CBR with

lack of intersectoral coordination leads to poor functioning of the services to disabled. Non-availability of evidence-based facts, lack of co-ordination between the Government and NGOs, the absence of a coherent community level strategy, limited competence and capacity of decentralizing services, limited models of good practices are the other lacunas in the system. Disability should be considered as an important issue by the Government so that this important public health problem can be tackled in the community. The services should cover all types of disabled who need rehabilitation services and it should be part of mainstream development in the community. A multi-sectoral approach including social integration interventions, health, education, and vocational programs are important issues related to rehabilitation services. Primary health care system must play a major role both as a provider and supporter, and should engage with initiatives such as early identification of impairments and providing basic interventions, referrals to specialized services such as physical, occupational, and speech therapies, prosthetics and orthotics, and corrective surgeries. The educational sector should be more inclusive by adapting newer techniques with respect to content of the curriculum, methods of teaching and ensuring that classrooms, facilities, and educational materials more accessible. Children with multiple or severe disabilities who might require extensive additional support may access education through the use of innovative methods best suited to their context. Collaboration with the employment and labor sectors is essential to ensure that both youth and adults with disabilities have access to training and work opportunities at community level. Productive and decent work in a conducive environment is essential for the social and economic integration of individual persons with disability (PWDs).

Monitoring and Evaluation in the service delivery should be strengthened with information dissemination related to impact on disabled, community mobilization, opportunity for education, opportunity for work, transfer skills to community level, program activities, and involvement of disabled people. Research with respect to services, fund allocation, cost-effectiveness, manpower, training, and technical aid of disabled people should be strengthened. One of the biggest challenges is providing rehabilitation services to the unreached persons with disabilities living in rural areas and small towns.

Recommendations

1. Advocacy for mainstreaming the systems and services. It requires commitment across all sectors and built into new and existing legislation, standards, policies, strategies, and plans.
2. Invest in specific programs and services for people with disabilities. In addition to mainstream services, some people with disabilities may require access to specific measures, support services, or training. In this process, involvement of persons with disability is of paramount importance as they give insight into their problems and suggest possible solution.
3. Capacity building of health care providers and program

managers. Human resource capacity can be improved through effective education, training, and recruitment. A review of the knowledge and competencies of staff in relevant areas can provide a starting point for developing appropriate measures to improve them. Manpower generation by promoting new courses and initiating degree and diploma courses like Physical Medicine and Rehabilitation will address the problem of shortage of manpower in long run.

4. Focus on educating disabled children as close to the main stream as possible.
5. Increase public awareness and understanding of disability. Governments, voluntary organizations, and professional associations should consider running social marketing campaigns that change attitudes on stigmatized issues such as HIV, mental illness, and leprosy. Involving the media is vital to the success of these campaigns and to ensuring the dissemination of positive stories about persons with disabilities and their families.
6. Generating representative community-based data will help to plan and execute appropriate measures to address the problems of persons living with disability.
7. Strengthen and support research on disability.

Research is essential for increasing public understanding about disability issues, informing disability policy and programmes, and efficiently allocating resources. Some of the important areas of research can be quality of life and well-being of people with disabilities; barriers to mainstream and specific services, and what works in overcoming them in different contexts; accessibility and universal design programmes appropriate for low-income-settings.

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